Welcome to FH Europe Foundation’s March 2025 edition of Heart Beat.

FH Europe Foundation March 2025 Heart Beat Newsletter

Welcome to the March edition of the Heart Beat newsletter!

This month was a powerful demonstration of what our community can achieve together. From the fourth annual **Lp(a) Awareness Day** to the first-ever **Lp(a) Global Summit**, March 2025 was dedicated to raising awareness and sparking international dialogue about this overlooked but critical inherited risk factor. Our Lp(a) awareness campaign reached new heights this year, with content shared in **22 languages**, thanks to the incredible efforts of our Network members, Ambassadors, Partners and Friends.

Meanwhile, our Network members organised meaningful activities in their countries, from health days and expert discussions to screenings, storytelling, and awareness weeks. Their efforts brought cardiovascular health issues, including elevated Lp(a), FH, and inherited lipid conditions, into the spotlight in diverse and powerful ways. Congratulations to Global Heart Hub, whose manifesto won a major international award and was featured in two prominent journals—another important milestone for patient-led advocacy.

Our partners have also been active on the European stage. From launching new parliamentary groups and campaigns to advancing discussions on EU4Health, data policy, and rare diseases, their work continues to push cardiovascular and rare disease priorities forward. This newsletter captures those highlights and more, reflecting a month full of action, connection, and collective progress.

Enjoy the read and have a wonderful week ahead!

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FH EUROPE FOUNDATION
NEWS

Thank you for making Lp(a) Awareness Day 2025 a success!

On March 24, we marked the fourth annual Lipoprotein(a) Awareness Day, drawing attention to one of the most common yet overlooked inherited risk factors for early cardiovascular disease and stroke.

Thanks to the power of our international community, **our informative content was shared in 22 languages across countless social media posts.** To our Network, Ambassadors, and everyone who helped us spread the word: **thank you**. Your support made a real difference.

Elevated Lp(a) affects 1 in 5 people globally—yet few know about it. Together, we are changing that.

Let’s continue raising awareness and pushing for early detection, better policies, and treatment access. Because knowledge saves lives.

Read more about it **here**.

First-Ever Global Summit on Elevated Lp(a) – Addressing One of the Biggest Unmet Needs in Cardiovascular Health

We made history! On 24–25 March 2025, Brussels hosted the *first-ever Global Summit on Elevated Lipoprotein(a) [Lp(a)]*, bringing together more than 60 of the world’s leading scientists, clinicians, policymakers, and patient advocates under one roof to ignite a new era of cardiovascular prevention.

Held under the patronage of the Polish EU Presidency and in celebration of Lp(a) Awareness Day, this landmark event was nothing short of extraordinary. From lived experiences to cutting-edge science, every voice in the room was united around one clear, urgent message “Test. Test. Test.”

Uniquely patient-powered and evidence-backed, the Summit gave centre stage to those living with elevated Lp(a), amplifying personal stories that moved hearts and minds. Their resounding call to action echoed throughout the sessions and shaped the Summit’s outcomes, including the historic Brussels International Declaration on Lp(a)—a bold policy roadmap to integrate Lp(a) testing into national cardiovascular strategies.

With scientific direction led by Prof. Florian Kronenberg (Austria) and coordinated by the Lp(a) International Task Force and FH Europe Foundation, the Summit featured Prof. Zanfina Ademi unveiling the first International Cost-Effectiveness Study on Lp(a) Testing.

We were honoured by strong support from EU policymakers, with inspiring leadership from MEP Romana Jerković, Chair of the MEP Cardiovascular Health Group, who passionately committed to taking the Brussels Declaration forward. MEP Adam Jarubas, Chair of the European Parliament Health Committee (SANT), who called for Lp(a) to feature prominently in the upcoming European Cardiovascular Health Plan and highlighted the urgent need to tackle health inequalities across the EU. The Summit aligned with the EU's top health priorities, including the upcoming European Health Data Space (EHDS) and December 2024 Council Conclusions on Cardiovascular Health as presented by the EU Health Commissioner, Olivér Várhelyi

The Brussels International Declaration on Lp(a) sets forth five bold policy asks. This declaration has the potential to transform the cardiovascular landscape globally making routine testing for Lp(a) the norm, not the exception.

This historic event would not have been possible without an incredible coalition of partners: *European Alliance for Cardiovascular Health* • *World Heart Federation* • *International Atherosclerosis Society* • *European Society of Atherosclerosis* • *Global Heart Hub*

With support from our industry partners:
Amgen • Novartis • Roche Diagnostics • Silence Therapeutics

Read more about it **here**.

Lp(a) 24th March AWARENESS DAY

WEBINAR

FH Europe Foundation

The Cost-Effectiveness of Lp(a) Testing and
the Brussels International Declaration on Lp(a) Testing and Management

What does this mean at a country level and how can our community be involved

31 MARCH 2025, 6 - 7 PM CET

Moderated by

Prof. Florian Kronenberg
Austria

Prof. Zanfina Ademi
Australia

Inese Maurina
Latvia

Nicola Beglington
Austria

To further the conversation initiated on Lp(a) Awareness Day and at the Lp(a) Global Summit, we held a special webinar today, titled:

The Cost-Effectiveness of Lp(a) testing and the Brussels International Declaration on Lp(a) Testing and Management
What does this mean at a country level and how can our community be involved

Moderated by **Nicola Bedlington**, this session explored key takeaways from the Lp(a) Global Summit, including new research commissioned by the FH Europe Foundation on the cost-effectiveness of Lp(a) testing and the importance of the Brussels International Declaration on Lp(a) Testing and Management. Speakers **Prof. Florian Kronenberg (Austria), Prof. Zanfina Ademi (Australia), and Inese Mauriņa (Latvia)** shared their impressions from the Summit and perspectives on how the findings could support policy change and action at the national level.

Stay tuned, the recording will be available soon!

Galaxy Forces United: For HoFH Awareness Day

HoFH Awareness Day is fast approaching, and this year's theme—**Galaxy Forces United: For HoFH Awareness Day**—reminds us of the strength, resilience, and unity within our global community.

Like stars in a galaxy, every individual affected by HoFH—patients, families, advocates, healthcare professionals, and researchers—shine on their own but is part of something much greater. Though we may be spread across the world, we are united in our mission: raising awareness, advancing treatment, and fostering hope.

HoFH may be rare, but together we are a powerful force. This HoFH Awareness Day, let's honour our shared purpose and collective energy.

Join our network call on April 2 at 15:00 CET to connect, collaborate, and prepare for an impactful Awareness Day on **May the 4th.**

Register for the call **here**.

The Urgent Call for Rare Disease Action at the European Parliament

On March 5, the event Impact of Rare Diseases: More Than You Can Imagine took place at the European Parliament, reinforcing the message that patients with rare diseases, including HoFH and FCS, cannot wait for faster diagnoses, better treatments, and equitable care.

Co-hosted by MEPs Stine Bosse and Adam Jarubas with EURORDIS-Rare Diseases Europe, the event marked Rare Disease Day 2025 with calls for stronger EU policies and funding. FH Europe Foundation was represented by Magdalena Daccord and Maja Bartoszewicz-Moritz.

Adéla Odrihocká shared a powerful testimony on the impact of delayed diagnoses. Tim Wilsdon presented new data showing that rare diseases cost the EU €250 billion annually—six times more than non-rare diseases. Investing in screening, genetic testing, and specialist care is essential.

MEPs highlighted the need for cross-border collaboration, stronger newborn screening policies, and holistic care. EURORDIS called for a European Action Plan to drive measurable progress.

FH Europe Foundation stands with the rare disease community in demanding urgent action. Every day without it puts lives at risk.

Watch the recording of the event **here** or read more about it **here**.

Public Advocacy Webinars on the Council Conclusions & the European Cardiovascular Health Plan

Cardiovascular diseases (CVDs) remain the leading cause of death in Europe, responsible for nearly 4 million deaths each year. Recognising the urgent need for action, the Council of the European Union adopted key conclusions on 3 December 2024, calling for stronger efforts in CVD prevention and management. The following day, the EU announced its intention to develop a European Cardiovascular Health Plan, marking a significant milestone for cardiovascular health across Europe.

To support patient organisations, advocates, and the public in understanding these developments and engaging in the policymaking process, FH Europe Foundation, in collaboration with EACH (European Cardiovascular Health Alliance) and its Partners, is launching a series of public advocacy webinars.

Upcoming Webinars – Save the dates! Registration starts soon.

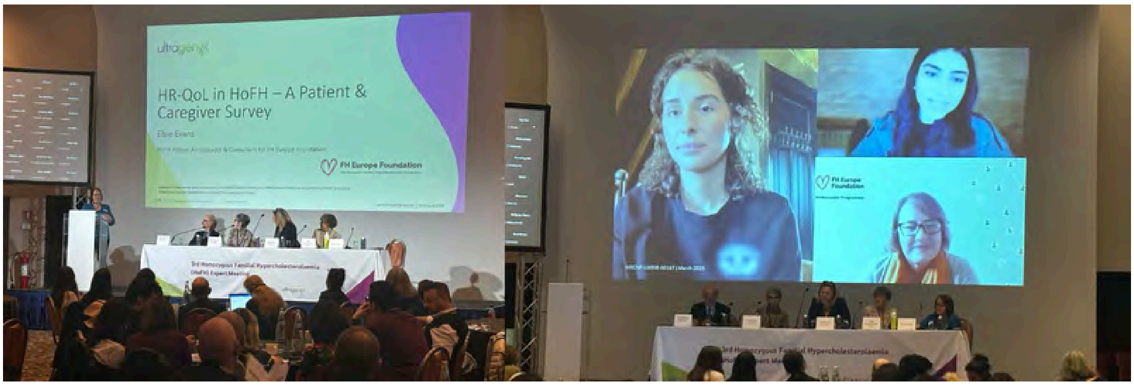
- **May 8, 2025**
- **May 30, 2025**
- **June 19, 2025**

Each 45-minute session, including a 15-minute Q&A segment, will provide clear insights into these critical topics. Participants will learn about the significance of the Council Conclusions, the objectives of the European Cardiovascular Health Plan, and the importance of national-level engagement to ensure effective implementation.

The webinars will feature expert speakers, including policymakers, representatives from EACH, patient groups, and potentially Members of the European Parliament. The discussions will focus on equipping patient organisations and individuals with the knowledge and tools to advocate for stronger cardiovascular health policies across Europe.

More details, including registration information, will be available soon. Join us to gain valuable insights and contribute to shaping the future of cardiovascular health policy in Europe.

Read more about it **here**.



Reflecting on an Inspiring HoFH Expert Meeting in Milan

The 3rd HoFH Expert Meeting in Milan brought together over 100 experts to discuss the latest data and developments in HoFH and rare lipid disorders. The exchange of knowledge and clinical experiences was invaluable, reinforcing the urgency of improving diagnosis, treatment, and care.

FH Europe Foundation contributed to the discussions with a presentation on Patient Perspective and Lived Experience of HoFH, prepared by Elsie Evans, FHEF Ambassador Programme Manager, together with HoFH Patient Ambassadors – Chyrel Lichaa and Olivia de Graaf, Maja Bartoszewicz-Moritz – FHEF Rare Diseases Project Manager and Magdalena Daccord, CEO of FHEF. Ensuring the patient voice is heard remains central to FH Europe's mission to drive meaningful progress.

Key sessions highlighted critical advancements, including Sex Differences in LDL-C: A Life Course Approach, which examined how cholesterol levels and risks vary by gender, and FH Screening – FH Kids, emphasising the importance of early detection and intervention in children. These discussions underscored the need for tailored approaches in HoFH care.

A special thank you to Ultragenyx for fostering open dialogue and collaboration, as collaborations like these drive real change. Thank you to all participants, your insights, engagement, and commitment to advancing HoFH care were truly inspiring.

Beyond Cholesterol: Why Weight Matters in Familial Hypercholesterolaemia

On March 4, World Obesity Day, FH Europe Foundation highlighted emerging research on the link between weight and heart health in people with familial hypercholesterolaemia (FH). While cholesterol had remained the primary concern, new findings suggested that weight also played a crucial role.

A study from the FH Studies Collaboration (FHSC), led by Dr Amany Elshorbagy, examined over 35,000 FH patients across 50 countries. The findings, published in the European Heart Journal, showed that more than half of adults and a quarter of children with FH were overweight or obese. Those with obesity had higher rates of coronary artery disease and stroke, even when cholesterol levels and medication use were accounted for.

This research reinforced the importance of a holistic approach to FH management—extending beyond cholesterol-lowering treatments to include personalised weight and lifestyle strategies.

Read more about it here.

International Women's Day 2025: Accelerate Action for Women's Heart Health

On International Women's Day, FH Europe Foundation highlighted the urgent need for better heart health care for women. While progress had been made in gender equality, millions of women and girls still faced significant barriers—including in healthcare.

Women with familial hypercholesterolaemia (FH), homozygous FH (HoFH), familial chylomicronaemia syndrome (FCS), and elevated lipoprotein(a) [Lp(a)] often experienced delayed diagnoses, underestimated risks, and limited access to care. Despite cardiovascular disease being the leading cause of death among women, lipid disorders remained widely overlooked.

This IWD2025, FH Europe Foundation called for action—earlier detection, better treatments, and equal access to life-saving care. Many community members participated by sharing their photos in support of women's heart health awareness.

The fight for equity in heart health continued, ensuring that every woman received the care she deserved.

Read more about the campaign **here**.

FH Europe Foundation Endorses Position Paper on Academic Biobanks and Patient Participation

FH Europe Foundation proudly endorses the position paper "Strengthening Academic Biobanks and Patient Participation for Biomedical Research," developed by organisations including the German Biobank Node (GBN) and the German Biobank Alliance (GBA). This document highlights the essential role of centrally organised academic biobanks in advancing biomedical research and improving patient care.

As a community dedicated to supporting individuals affected by familial hyperlipidaemias (HeFH, HoFH, elevated Lp(a), and FCS), we recognise the immense value of high-quality, well-funded biobanks in driving medical breakthroughs. The paper's focus on sustainable funding, quality assurance, and patient participation aligns closely with our mission to improve health outcomes through research and innovation.

We fully support the call for greater cooperation with academic biobanks and stronger patient involvement in biomedical research. These measures will not only advance scientific knowledge but also empower patients by integrating their voices into research efforts.

Read more about it **here**.

FH Europe Foundation Announces First Ambassador Programme Training

We are thrilled to announce the extension of FH Europe Foundation's Ambassador Programme with our first in-person training event taking place in Cyprus on 10-11 April 2025. This two-day event will bring together Certified Patient Ambassadors and local advocates for expert-led sessions on familial hyperlipidaemias, early screening, cardiovascular disease prevention, and advocacy strategies.

Participants will have the opportunity to engage in interactive workshops designed to enhance their knowledge and skills, empowering them to drive meaningful change. This milestone event marks the first in-person component of the programme, dedicated to equipping patient representatives with the tools needed to make a lasting impact in their communities.

The training is organised as part of the **PERFECTO** project, co-funded by the European Union as part of the EU4Health grant, further strengthening efforts to improve patient advocacy and early detection of cardiovascular diseases.

Stay tuned for more events, and if you are interested in joining this hybrid Ambassador training and the wider Ambassador programme, please contact **elsie@fheurope.org**.

PATIENT
STORY

Connecting the Dots Between Family and Heart Health

Renate Kaal-Poppelars' journey with heart health began after experiencing pre-eclampsia. Despite pushing for follow-ups, she later developed chronic hypertension. Her husband's familial hypercholesterolaemia (FH) led them to test their children, revealing their son's elevated Lp(a)—a risk Renate unknowingly shared.

After years of searching, she was also diagnosed with INOCA, highlighting the gaps in women's heart care. Her story underscores the urgency of early detection and advocacy. This is why initiatives like Lp(a) Awareness Day and the Lp(a) Global Summit 2025 matter—to drive change in testing, policies, and care.

Read her story **here**.

NETWORK
NEWS

Austria - FHChol

Austria FHChol Hosting a Memory Walk in Honour of Gaby Hanauer-Mader

On March 29, 2025, FHChol will hold its annual Gaby Hanauer-Mader Memorial Hike in the Perchtoldsdorfer Heide. The event honours the memory of Gaby Hanauer-Mader, former FH Europe President and passionate advocate for the FH community. Participants will hike to the Kammersteiner Hütte for a lunch break, followed by a social gathering at a local Heuriger in Perchtoldsdorf. This cherished tradition brings together the community to remember Gaby's enduring impact and dedication.

Read more about it **here**.

Czechia - ČAKO

ČAKO Promotes Cardiovascular Health at Prague Hospital

In March, ČAKO hosted a successful Health Day at the Central Military Hospital in Prague, drawing a full lecture hall of doctors, nurses, and patients. The event focused on cardiovascular health, including Lp(a) and familial hypercholesterolaemia (FH), and offered on-site cholesterol and Lp(a) testing. Several attendees were identified with high Lp(a) levels and referred for follow-up care. The event featured expert talks and moving patient stories shared by CAC Vice-Chair Martina Motshagen and Board Member Zdeněk Fejfar. A big thank you to the hospital team and all collaborators who made the event possible.

Read more about it **here**.

Ireland - Croí

Croí Launches PhD Scholarships for Stroke Research

Croí has announced the launch of two PhD scholarships to advance stroke prevention and recovery, thanks to the generous support of the Joe and Helen O'Toole Charitable Trust (Tuam). The first recipient, Bríd Spillane, a specialist in neurorehabilitation, will lead research at the University of Galway focused on improving everyday mobility for stroke survivors. Running over eight years, the scholarships aim to drive long-term progress in stroke care. Croí continues to strengthen its commitment to innovation in cardiovascular health through meaningful partnerships and patient-focused research.

Read more about it **here**.

Poland – EcoSerce

A Major Success in FH Screening: A Joint Effort of Patient Organisations and Clinicians

Poland is making a significant breakthrough in the early detection of familial hypercholesterolaemia (FH). The introduction of a nationwide FH screening programme is a major success, achieved through the dedicated efforts of patient organisations—including EcoSerce, a member of FH Europe—as well as leading clinicians.

A draft regulation on guaranteed healthcare services has been submitted to the Government Legislation Centre, setting the stage for FH screening as part of routine health check-ups in primary care (POZ) during the mandatory preschool preparation year. In practice, this means that children aged 5 to 7 will undergo testing.

The goal of the screening programme is to improve access to FH diagnostics, increase the number of diagnosed patients, and raise awareness of the disease.

The screening will include a lipid panel (lipidogram), which assesses blood levels of total cholesterol, LDL cholesterol, HDL cholesterol, triglycerides, and non-HDL cholesterol.

In Poland, FH affects up to 200,000 individuals, yet only 2-3% of cases have been diagnosed. This condition is often described as a ticking time bomb, as it significantly increases the risk of premature cardiovascular disease if left untreated.

By introducing systematic screening at an early age, Poland aims to improve early detection and intervention, ultimately reducing the long-term health burden of FH.

Atzīmējot Starptautisko Lipoproteīna(a) atpazīstamības veicināšanas dienu 24. martā, biedrība ParSirdi.lv, kopā ar kardiologiem, **aicina pievērst uzmanību** šim mazāk zināmajam, bet izplatītajam **sirds un asinsvadu slimību riska faktoram**, kas, savlaicīgi nediagnosticēts, var novest pie sirds artēriju aterosklerozes, infarkta, insulta vai aortas vārstuļa sašaurināšanās.

Latvia – ParSirdi.lv

Latvia Joins Global Effort to Raise Awareness of Lipoprotein(a)

To mark International Lipoprotein(a) Awareness Day on March 24, the ParSirdi.lv association, together with cardiologists, raised awareness about this lesser-known but widespread risk factor for cardiovascular diseases.

Cardiologist Prof. Gustavs Latkovskis (Pauls Stradiņš Clinical University Hospital, University of Latvia) said: *"We know that high LDL ('bad') cholesterol contributes to heart disease, but few people in Latvia are aware of Lp(a)'s significant impact on cardiovascular health. While high Lp(a) levels are not a disease in themselves, they are a major risk factor for future heart complications. That's why it's crucial to get tested early. Since Lp(a) levels remain stable throughout life, a single test is enough. Although medications for Lp(a) are still in development, those with high levels should focus on managing* *other risk factors—especially lowering LDL cholesterol, controlling blood pressure, and monitoring blood sugar. Even though lifestyle changes do not reduce Lp(a) directly, a healthy diet, exercise, and not smoking remain essential for overall heart health."*

Inese Mauriņa, Head of ParSirdi.lv, added:
"Cardiovascular diseases place a heavy burden on healthcare. Early prevention, diagnosis, and risk management are key to reducing heart disease-related consequences. As we mark International Lp(a) Awareness Day, we encourage everyone to check their Lp(a) levels and, if necessary, consult a doctor for next steps. This can help prevent avoidable heart health crises. Unfortunately, in Latvia, outpatient Lp(a) testing is not yet state-funded, but we hope that the upcoming Cardiovascular Health Improvement Plan will include the possibility of covering this essential risk factor diagnosis."

As part of the activities, a media campaign was carried out, including a including **a feature in one of Latvia's leading health magazines**, **article on ParHolesterinu.lv**, an **interview on Latvian Radio 1**, and **a report on Medicine.lv**. In addition, ParSirdi participated in the social media campaign organised by FH Europe Foundation and hosted an online discussion with cardiologist Prof. Gustavs Latkovskis. You can watch the recording **here**.

The Netherlands - Stichting VrouwenHart

VrouwenHart Highlights Lp(a) and Women's Cardiovascular Health

To mark Lp(a) Awareness Day, Stichting VrouwenHart shared insights from the article *"Lipoprotein(a) throughout life in women"*, with the help of FH Europe Foundation Patient Ambassador Renate Kaal Poppelaars. The piece highlights how genetically determined Lp(a) levels fluctuate across key life stages such as pregnancy and menopause, increasing cardiovascular risk. It reinforces the importance of testing Lp(a) at least once in life—especially for women with a family history of heart disease—and calls for a more gender-specific approach to cardiovascular care.

Read more about it **here**.

Singapore - FHCARE Singapore

Lipid and Lipoprotein(a) Awareness Week 2025: Advancing Knowledge for Better Care

Building on the success of Singapore's inaugural Lipoprotein(a) Awareness Day in 2024, which drew an impressive 600 attendees, FHCARE Singapore is proud to present the "Lipid and Lipoprotein(a) Awareness Week 2025." This expanded initiative led by Dr Wann Jiah Loh, is supported by leading doctors and allied health professionals. It aims to educate healthcare professionals and the public on key lipid concepts: LDL, Lipoprotein(a), and triglycerides, including familial hypercholesterolaemia and other genetic conditions. Highlights include Day 1 (22 April) at CGH Auditorium and Day 2 (23 April) at CGH Atrium. Recognised by FH Europe Foundation, this event underscores the importance of early intervention in lipid disorders.

Read more about it here.

Spain - Fundación Hipercolesterolemia Familiar

FHF Supports Documentary Premiere on Neonatal Screening

The Infanta Elena Hospital in Huelva hosted the premiere of "Life in a Drop", a documentary advocating for expanded neonatal screening, including for Familial Hypercholesterolaemia (FH). The film highlights the disparities in screening across Spain and the need for equal diagnostic opportunities for all newborns. During a post-screening discussion, experts and families emphasised the impact of early FH detection. As part of a pioneering study, 6,000 newborns were screened in Huelva, identifying 30 FH cases. The initiative, supported by FHF, may help advance national approval of FH screening at birth.

Read more about it here.

Spain to Host 10th Familial Hypercholesterolaemia Symposium

The Fundación Hipercolesterolemia Familiar will hold its 10th annual Familial Hypercholesterolaemia (FH) Symposium in Madrid on 24–25 April 2025, with in-person and virtual attendance options. This unique event brings together healthcare professionals focused on reducing cardiovascular disease in people with inherited lipid disorders, including heterozygous and homozygous FH and elevated Lp(a). The programme covers clinical updates, emerging therapies, real-world data from the SAFEHEART study, and topics such as newborn screening, risk stratification, and precision medicine.

Read more about it here.

Global Heart Hub

Global Heart Hub Wins Global Cardiovascular Award

Global Heart Hub received the Best Prevention award at the Global Cardiovascular Awards in London for its groundbreaking manifesto: “Achieving Early Detection and Diagnosis of Cardiovascular Disease.” The manifesto unites 125 patient advocates, 40 organisations, and leading experts to push for earlier CVD diagnosis. Project Lead Olive Fenton and Teresa Glynn accepted the award on behalf of GHH. This recognition highlights the power of collaboration and the importance of placing patients at the heart of global cardiovascular strategies.

Read more about it here.

Global Heart Hub Manifesto Published in IFCC Journal

Global Heart Hub’s manifesto on early detection and diagnosis of cardiovascular disease has been featured in the Electronic Journal of the IFCC. The article highlights the vital role of laboratory tests—especially NP testing—and emerging technologies in transforming CVD care. This follows the manifesto’s recent publication in the European Heart Journal, showing growing momentum and global relevance. The patient-led manifesto outlines a bold, multi-pronged strategy to reduce the burden of CVD and improve outcomes worldwide.

Read more about it here.

NEWS
FROM AROUND THE WORLD

The Critical Medicines Act: Strengthening Access to Essential Medicines in the EU

In March 2025, the European Commission proposed the Critical Medicines Act (CMA), a major step toward ensuring the availability, supply, and production of essential medicines across the EU. This initiative is particularly important for people with rare diseases, who often face difficulties accessing the treatments they need.

The CMA introduces strategic projects to support the production of critical medicines, collaborative procurement to improve distribution, and international partnerships to diversify supply chains. These measures aim to reduce shortages, enhance medicine security, and ensure that all EU citizens have reliable access to life-saving treatments.

A key element of the CMA is the Union List of Critical Medicines, managed by the European Medicines Agency (EMA), which prioritizes essential medicines for emergency care, chronic conditions, and rare diseases.

This Act is part of the broader European Health Union and complements the ongoing EU pharmaceutical legislation reforms, further strengthening Europe's healthcare system.

Read more about it **here**.

Data Saves Lives Shares Update on EHDS Regulation

The European Health Data Space (EHDS) regulation, set to take effect in March 2025, aims to improve patient access to health data while enabling its responsible use for research and innovation. It will allow individuals to manage their Electronic Health Records (EHRs) and support healthcare professionals in providing better-coordinated care.

For the FH Europe Foundation community, this is a major step forward in enhancing the diagnosis, treatment, and management of familial hyperlipidaemias (FH) and related conditions. By ensuring secure and seamless data sharing across the EU, the EHDS will strengthen patient care and drive research into rare diseases.

To make this regulation truly patient-centric, the European Patients' Forum (EPF) highlights the need for clear data access, transparency, privacy protections, and digital health literacy programs.

Read more about it here.

PARTNER
NEWS

The European Alliance for Cardiovascular Health - EACH

EACH to Launch MEP Cardiovascular Health Group at the European Parliament

EACH is proud to support the launch of the MEP Cardiovascular Health Group, an informal interest group in the European Parliament, chaired by MEP Romana Jerković (S&D, Croatia). The group will hold its inaugural meeting on April 23, 2025, in Brussels, offering MEPs the opportunity to connect with EACH partners, explore the year's work programme, and celebrate the release of the Alliance's new publication, *"A European Cardiovascular Health Plan: The Roadmap."* Further details on the launch event will be announced soon.

Read more about it here.

European Patients' Forum

EU4Health Civil Society Alliance Raises Concerns Over 2025 Work Programme Delays

The EU4Health Civil Society Alliance, representing over 30 health civil society organisations, has expressed serious concerns about the lack of information on the EU4Health work programme and operating grants for 2025.

As of now, no details or timeline have been provided regarding their publication or retroactivity. The delay could leave a significant part of 2025 uncovered, limiting the time available for CSOs and other stakeholders to implement key activities. This uncertainty threatens the effectiveness of initiatives that would typically span the full year.

Read more about it **here**.

EPF Launches “We Are Here” Campaign for a Patient-Centred Future

The European Patients’ Forum (EPF) has launched “We Are Here”—a campaign calling for stronger, structured patient involvement in shaping health policy across Europe. Highlighting the ongoing challenges in healthcare, including EU budget cuts and rising health inequalities, EPF advocates for health as an investment, not a cost. With over 20 years of experience bridging policymakers and patients with chronic conditions, EPF continues to push for fair, inclusive, and resilient health systems, placing patient voices at the heart of European decision-making.

Read more about it **here**.

EURORDIS

European Health Data Space: Adoption Complete

In March 2025, the European Health Data Space (EHDS) was officially published and took effect on March 25. This regulation creates a secure EU-wide system for exchanging health data, improving patient care, advancing research, and driving innovation.

- Enhancing Patient Care – EU citizens will gain secure access to their health records, while providers can retrieve data across borders.
- A Breakthrough for Rare Diseases – EHDS will help reduce diagnostic delays and improve research for 30M+ Europeans with rare diseases.
- EURORDIS Advocacy Reflected – Privacy safeguards, patient opt-outs, and interoperability were key priorities included.

With implementation beginning in 2028, EURORDIS will continue advocating for patient-focused health data policies.

Read more about it here.

Patient Organisations Warn Against EU Rollback on Patient Involvement in Medicines Regulation

On March 10, 2025, EURORDIS-Rare Diseases Europe and the European Patients’ Forum (EPF) urged EU Member States to protect meaningful patient involvement in the European Medicines Agency (EMA). Ongoing negotiations on EU pharmaceutical legislation risk reversing decades of progress in patient-centred regulation.

Proposals to grant patient representatives voting rights in the CHMP and PRAC are under threat. Removing them would reduce patients to observers rather than active contributors to decisions affecting their health and quality of life.

For 25 years, patient engagement has strengthened trust in the EMA. EURORDIS and EPF warn that stripping voting rights would be a major setback and urge policymakers to uphold patient representation in regulatory decision-making.

Read more about it here.

WORLD ADHERENCE DAY 27 MARCH

World Heart Federation—WHF

Marking the First-Ever World Adherence Day

On March 27, the World Heart Federation (WHF) launched the first-ever World Adherence Day, a global initiative to raise awareness about the importance of patient adherence in managing health conditions and improving outcomes.

Adherence is more than just taking medication. It involves tailoring personalised healthcare plans, fostering shared decision-making, and empowering individuals and caregivers to stay committed to their treatment. Non-adherence remains a significant public health challenge, often leading to complications, hospitalisations, and preventable deaths. Research shows that adherence can lower long-term mortality risk by up to 21%, reinforcing its life-saving impact.

- Improving adherence requires a collective effort:
- Healthcare providers must offer clear guidance and ongoing support.
- Patients should stay engaged in their treatment plans.
- Families, caregivers, and communities play a key role in encouraging adherence.

By working together, we can improve health outcomes, reduce cardiovascular risk, and ensure better disease management.

Read more about it **here**.

KNOWLEDGE
HUB

HTAR Training Sessions in May

What is HTA? Health Technology Assessment (HTA) is a way to evaluate the benefits and costs of medical treatments and technologies. It helps decide which health technologies are worth using.

HTAR Training Sessions in May: These are free and accessible Health Technology Assessment Regulation (HTAR) training sessions in May, available in four languages.

What will I learn in these training sessions? These sessions will provide an overview of the EU HTAR process and explain how patients can be involved at both national and European levels. Upon completion, participants will receive a certification of attendance and be listed as potential experts who could contribute to this new process.

Once you have completed the training, please share your certificate of participantion with the Ambassador Programme Manager at **elsie@fheurope.org**.

Register today and get equipped in HTAR:

- 📅 **May 7 (18:00 CEST) - HTAR Training in Portuguese in collaboration with** ENP Portugal**. Register** here**.**
- 📅 **May 13 (15:00 CEST) - HTAR Training in Czech in collaboration with** ENP Czechia**. Register** here**.**
- 📅 **May 21 (15:00 CEST) - HTAR Training in French. Register** here**.**
- 📅 **May 26 (10:00 CEST) HTAR Training in English in collaboration with** DiCE**. Register** here**.**

SAVE THE DATE

- **April 3** – ESC Preventive Cardiology 2025, Milan, Italy
- **April 7**- World Health Day
- **May 3** – EAS FH Paediatric Symposium 2025
- **May 4** – HoFH Awareness Day
- **May 4** – 93rd EAS Congress
- **May 17-18** – World Heart Summit, Switzerland
- **November 14-16** – FH Europe Foundation Annual Meeting, Croatia

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